ECFS Diagnostic Network Working Group
Coordinator: Nico Derichs, Berlin, Germany
https://www.ecfs.eu/ecfs_dnwg


Organizing Committee:

Jane Davies – Royal Brompton Hospital, London, UK
Nicholas Simmonds - Royal Brompton Hospital, London, UK

Nico Derichs – DNWG Coordinator
Sheila Scheinert – DNWG Assistant
Scientific Program

Thursday 11 February 2016

13.30 Arrive and coffee
14.00 Welcome – Jane Davies (London, UK)

Session 1: When it’s not CF: State of the art diagnostics for other chronic suppurative lung diseases
(Chairs: Nick Simmonds, Isabelle Sermet-Gaudelus)

14.05 Advances in imaging of ciliary defects: EM, tomography and immunofluorescence - Claire Hogg (London, UK)
14.35 An update in PCD genetics - Hannah Mitchison (London, UK)
14.55 Immune testing in bronchiectasis - Austin Worth (London, UK)
15.25 Secondary defects in CFTR in non-CF CSLD: myth or reality? Nasal PD and inflammatory cytokines in a cohort of patients with PCD - Suzanne Crowley (Oslo, Norway & London, UK)
15.50 Discussion

16.00 - Coffee break –

Session 2: Current practice and challenges of diagnosing CF in ...
(Chairs: Nico Derichs, Jacquelien Noordhoek)

16.30 Norway – Olav Trond Storøsten (Oslo, Norway)
16.45 Hungary – Reka Bodnár (Budapest, Hungary)
17.00 Greece – Elpis Hatzigorou (Thessaloniki, Greece)
17.15 Tunisia - Samia Hamouda (Tunis, Tunisia)
17.30 How can CF Europe support diagnosing CF in European countries?
   (Jacquelien Noordhoek, CF Europe)
Friday 12 February 2016

Session 3: Precisely defining and communicating the diagnosis of CF and associated phenotypes

(Chairs: Kris De Boeck, Carlo Castellani)

9.00 CFF Diagnosis Consensus Statements 2016:
   - Screened populations - Clement Ren (Indianapolis, USA)
   - Non-Screened populations - Patrick Sosnay (Baltimore, USA)

9.45 CFTR-related disorder: extended use as label for multiorgan CF-like disease
   (“CFSPID developing symptoms/CFTR dysfunction/atypical CF”) not fulfilling CF diagnostic criteria?
   - Pro: Kevin Southern (Liverpool, UK), Con: Jürg Barben (St. Gallen, Switzerland)

10.15 Discussion

10.50 - Coffee break -

11.20 Why a diagnosis of CFSPID can be harder to handle than CF and how could we do better?
   - Jane Davies, Dr Michele Puckey (Consultant Paediatric Psychologist) and CFSPID parents (London, UK)

12.00 CFSPID to CF: The perspective of the adult physician - Nicholas Simmonds (London, UK)

12.30 ECFS Diagnosis Consensus Delphi Process 2016 - Nico Derichs (Berlin, Germany)

13.00 - Lunch break –

Session 4: Diagnostic use of CFTR Biomarker & Genetics

(Chairs: Michael Wilschanski, Inez Bronsveld)

14.00 Real life practice of sweat testing in Europe: Results of the ECFS DNWG survey and next steps –
   - Natalia Cirilli (Ancona, Italy)

14.30 How to define a CF-typical NPD? Multicenter reference data from the diagnostic ECFS NPD SOP validation study - Isabelle Sermet-Gaudelus (Paris, France)
15.00  How to define a CF-typical ICM? Multicenter reference data from the diagnostic ECFS ICM SOP validation study and the ECFS CTN ICM certification process – Sheila Scheinert (Berlin, Germany)

15.30  Young Investigator 1: Diagnostic application of ECFS SOPs for NPD and ICM to patients with questionable CF or CFTR-related disorder - Michael Klosinski (Berlin, Germany)

15.45  Young Investigator 2: Organoids in a challenging diagnosis of atypical Cystic Fibrosis
Barbara Bosch (Leuven, Belgium)

16.00  - Coffee break –

16.30  Young Investigator 3: Combining standardized and new CFTR functional tests for diagnosis – Silvia Vercellone (Verona, Italy)

16.45  Young Investigator 4: *Ex vivo* differentiated nasal epithelium as a model for the functional characterisation of splicing mutations in the *CFTR* gene and test of new targeted therapies?
Anne Bergougnoux (Montpellier, France)

17.00  CFTR3: Collection of clinical phenotype data in subjects with rare *CFTR* mutations –
Elke De Wachter (Brussels, Belgium)

17.30  Quantifying CFTR function in intestinal organoids of subjects with rare *CFTR* mutations –
Anabela Ramalho (Leuven, Belgium)

18.00  Complete *CFTR* gene mutation analysis in European patients with CF –
Kris De Boeck (Leuven, Belgium)
Saturday 13 February 2016

Session 5: Clinical trials and outcome measures in CF

(Chairs: Kevin Southern, Elke De Wachter)

9.00  CFTR gene therapy: what does the future hold? – Uta Griesenbach (London, UK)

9.30  Sweat test variability in real life – Francois Vermeulen (Leuven, Belgium)

10.00 Lung clearance index: Update on the ECFS CTN Core facility and plans for a multicenter clinimetrics study – Jane Davies (London, UK)

10.25 Further understanding differences between SF6 and nitrogen-based MBW techniques – Katie Bayfield (London, UK)

10.50 Gastrointestinal outcome measures in CF clinical trials - Michael Wilschanski (Jerusalem, Israel)

11.15 - Coffee break –

Session 6: The ECFS Diagnostic Network Working Group - a growing global network

(Chairs: Jane Davies, Sheila Scheinert)

11.45 Diagnosing CF in Africa – Refiloe Masekela (Durban, South Africa)

12.15 Young Investigator 5: A Molecular Investigation of Cystic Fibrosis in South Africa – Cheryl Steward (Pretoria, South Africa)

12.30 Young Investigator 6: Pulsed direct and constant direct currents in the pilocarpine iontophoresis sweat chloride test - Carla Gomez (Campinas, Brazil)

12.45 1st Latin American Newborn and Early Screening of CF patients (LANES) Meeting 2015: Summary and DNWG collaboration - Ana Kotnik Pirs (Ljubljana, Slovenia)

13.00 Conclusion & DNWG perspectives – Nico Derichs (Berlin, Germany)

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